Research Summary

Developing a definition of neurodisability

This research summary was written by PenCRU and members of the PenCRU Family Faculty

Key findings

- A definition of neurodisability was broadly agreed among health professionals and parents of children with neurological conditions.
- More than 200 health professionals from a wide range of professions involved in the care of children affected by neurodisability contributed to the definition in an online survey.
- A small number of international colleagues was consulted; most of them agreed with the definition.
- The definition will enable people with neurodisability to be grouped for research, to organise and evaluate services, and other purposes.

Definition of neurodisability

Neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion and behaviour.

Who carried out this research and why?

This research was part of a project examining appropriate health outcomes for children with neurodisability. We needed a definition of neurodisability that could be understood by families and professionals, so that everyone was clear which children and young people were being considered.

The study was led by researchers at the Peninsula Cerebra Research Unit (PenCRU) at the University of Exeter Medical School in collaboration with two paediatricians, and four parents from the PenCRU Family Faculty. The PenCRU Family Faculty is parents of disabled children, mostly resident in Devon, who have indicated a willingness to be involved in research (see www.pencru.org for more information).

The project was commissioned by the National Institute for Health Research (NIHR).

Background

Neurodisability is a term used to describe a group of particular conditions. However, neurodisability has not been defined and there is no agreement as to which conditions are included.
The lack of an agreed definition is a major barrier to communication between services, and also research about this group of children.

**What did we do?**

The method we used is called a Delphi survey. A Delphi survey is a method to reach consensus, or agreement. Participants are presented with statements and asked to rate their agreement or disagreement, and make comments. The researchers collect the answers and use the feedback to reformulate the statements and then present them again to participants. The process is repeated until at least 67% of the group agrees.

The team developed an initial definition in collaboration with parents of children with neurological conditions. This definition was used as a starting point for the Delphi survey. There were three rounds of the survey before we were satisfied that there was broad agreement with the definition.

**Who took part in the study?**

We sent out invitations through child development teams and specialist professional societies in England. Health care professionals volunteered to participate by registering online.

Once we had developed a definition that was acceptable to participants in England, we asked international experts for their opinion.

**What did we find?**

**Which professionals were included?**

In total, 309 health professionals registered interest in taking part; 245 took part in round 1, 242 in round 2, and 237 in round 3. Participants were from a wide range of professions: e.g. nurses, orthotists, paediatricians, physiotherapists, psychologists, surgeons, and speech and language therapists.

**Refining the definition**

Agreement with the proposed definition was extremely high in every round: 89% (round 1), 90.1% (round 2), and 93.6% (round 3).

We adapted the definition based on feedback and offered two versions: one with and one without examples of specific conditions. Three out of four professionals preferred a definition without examples, mostly to avoid discussion about the choice of the examples.

We consulted with parents on the team. They thought the examples may help some parents but also considered that they could be misleading:

- if a child’s diagnosis is not listed,
- if the child’s diagnosis is different from the examples given,
- or if no specific diagnosis has yet been made.

We received 22 responses from international colleagues, and 18/22 agreed or strongly agreed with the definition.

The final recommended definition is as presented on the first page.

**Who reviewed our research to make sure it was done well?**

This study is published in a journal called Developmental Medicine and Child Neurology. Before the journal accepted the study to be published it asked independent experts to look at the paper and decide whether it had been properly done and whether it was important enough to publish.

**What could be done next?**

- The definition might also apply to adults; however, this would need to be confirmed.
- Children and young people, social care and educational professionals could be consulted about whether the definition is meaningful for them as well.
The team that carried out the research are: Chris Morris, Astrid Janssens, Richard Tomlinson, Jane Williams and Stuart Logan with support from parents from the PenCRU Family Faculty.

Dr Morris, Dr Janssens and Prof Logan are all part of PenCRU and the NIHR Collaboration for Leadership in Applied Health Research and Care of the South West Peninsula (PenCLAHRC) at the University of Exeter Medical School. Dr Tomlinson is a Consultant Paediatrician at Royal Devon and Exeter NHS Foundation Trust, and Dr Williams is a Consultant Paediatrician at Nottingham University Hospitals NHS Trust.

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